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ABSTRACT

This guidebook is offered as a "road map" for parents who wish to be involved in shaping public policy regarding early intervention for children with disabilities, by participating in state or local Interagency Coordinating Councils (ICCs). Parents who are current or former members of state ICCs share their stories, learning, and thoughts about what it means to be a parent representative. Each chapter begins with a quotation from "Alice in Wonderland" by Lewis Carroll and ends with a quotation from "Alice in ICC-Land," a play written by Jeanette Behr. The story of Alice was chosen because of its many useful parallels with parents' experience on state ICCs, as they venture out from their everyday reality to a land where things are not always what they seem. Eight chapters focus on: (1) the role of parent representative and ways to find a mentor; (2) the relationship between the ICC and the lead agency; (3) appropriate ways in which to relate the experience of having a child with a disability; (4) the history and nature of early intervention; (5) how to get respect, information, and support; (6) preparing for the first ICC meeting; (7) taking on new roles with increased experience and identifying issues and other Council members who will listen; and (8) becoming a mentor and determining one's effectiveness. Appendices contain a copy of the play "Alice in ICC-Land"; a statement on full participation of families; findings from a survey of ICC parents; information on parent reimbursement; a list of resource organizations; and recommendations concerning ICC parent development and support. (JDD)

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Go Ask Alice:

A Guidebook for Parents Serving on State and Local Interagency Councils

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Said the Duchess.... — 'Be what you would seem to be'; or, if you'd like it put more simply — 'Never imagine yourself not to be otherwise than what it might appear to others that what you were or might have been was not otherwise than what you had been would have appeared to them to be otherwise.'"

"I think I should understand that better," Alice said very politely, "if I had it written down; but I can't quite follow it as you say it.

Go Ask Alice:

A Guidebook for Parents Serving on State and Local Interagency Councils

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One of the many challenges presented by P.L. 99-457, Part H, is the development of new kinds of relationships between parents and professionals. New ways of relating are needed not only in planning and providing services to individual infants and toddlers, but also at the policy level, as parents and professionals serve together on Interagency Coordinating Councils (ICCs) at the state and local level.

Parents serving on state-level ICCs for early intervention in the Great Lakes states (Illinois, Indiana, Michigan, Minnesota, Ohio, Pennsylvania and Wisconsin) have participated in a regional networking activity since the fall of 1989. The activity has been facilitated by the Great Lakes Area Regional Resource Center (GLARRC) in response to needs identified by parent representatives to its Advisory Committee. The activity has focused on addressing the needs of ICC parents for information, support and training through their linkage with each other, existing parent training and information centers (PTIs) and other resources.

A play entitled *Alice in ICC-Land* [1] was written in the summer of 1990 by Jeanette Behr, parent representative to and Chairperson of the Minnesota ICC, with assistance from Shirley Kramer of the Minnesota ICC and Dennis Sykes of GLARRC. The idea for the play developed during two regional meetings of ICC parents and parent training center representatives, sponsored by GLARRC in February and May of 1990. It was given its premiere performance on September 17, 1990, at a regional ICC parent conference in Bloomington, Minnesota. This susbsequent guidebook has become a joint project of GLARRC and the Early Integration Training Project, which is providing the resources to complete the development of this guidebook and other materials, and will be using this guidebook as part of its federally funded training efforts in Ohio.

The guidebook is offered as a road map to ICC-Land for parents who wish to be involved in shaping public policy regarding early intervention, by participating in state or local Interagency Coordinating Councils. In it parents who are current or former members of state ICCs share their stories, learning and thoughts about what it means to be a parent representative. With a tip of the hat to Jeanette and Shirley, we have borrowed and extended the images of *Alice in ICC-Land* for this guidebook. Each chapter in this guidebook begins with a quotation from the original *Alice in Wonderland* and ends with a quotation from *Alice in ICC-Land.* The story of Alice in Wonderland was chosen by the parents because of its many useful parallels with their experience on state ICCs. Alice seems an apt image for parents venturing out from their everyday reality to the sometimes strange new land of the ICC, where things are not always what they seem.

The sometimes humorous adaptation of this tale is not meant to minimize the very important role of parents on state and local ICCs, but rather to empower and enable their more effective participation. We hope that the views expressed will be accepted in the spirit and humor in which they are offered.

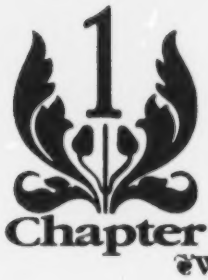
❦ This booklet represents a true team effort, involving all those who have participated in the meetings and conference calls in this activity for the past two years. Material was collected and assembled by Dennis Sykes, of GLARRC, Cindy Norwood, Executive Director of SKIP of Ohio and a parent representative to the Ohio ICC, Diane Gerst, a parent consultant for Ohio's Family Information Network and a local ICC parent representative, and Leah Holden, Associate Director of the Association for Retarded Citizens-Ohio. Asonya McKinney Brown, Brown Mountain Graphics contributed graphics and layout.

❦ In addition to Cindy, ICC parent representatives who provided personal opinions, experiences and stories are Jeanette Behr, member and current Chairperson of the Minnesota ICC; Bob Boyce of the Pennsylvania ICC; Linda Colson Perlstein, member of the Illinois ICC; Rachel Grant, Wisconsin ICC member; Kathy Richardson, member of the Indiana ICC; Deb Russell, of the Michigan ICC; and Sue Walter, member of the Illinois ICC. Their thoughtful comments give life and richness to this booklet.

❦ Many others have contributed to this document. Special thanks are extended to Paula Goldberg, Director of PACER Center in Minnesota; Louise Thieme, of the Pennsylvania Parent Education Network; Alice Kelly, of the Illinois Alliance for Exceptional Children and Adults; Richard Burden of INSOURCE; Sue Pratt of Michigan CAUSE; and Liz Irwin of the Wisconsin Parent Education Project.

❦ We would also like to respectfully acknowledge Lewis Carroll and John Tenniel, the author and illustrator of the original "Alice in Wonderland", without which the inspiration and the substance of this parody would not have been possible.

About the contributors:



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In another moment down went Alice after the rabbit, never once considering how in the world she was to get out again.

"It was much pleasanter at home," thought poor Alice, "when one wasn't always growing larger and smaller, and being ordered about by mice and rabbits. I almost wish I hadn't gone down that rabbit-hole — and yet — and yet — it's rather curious, you know, this sort of life!"

Chapter 1

"Down the Rabbit Hole"

In which Alice gets her ICC appointment, finds a mentor, and masters the reimbursement process

What is the position of a parent representative all about?

Parents' perspective is based on day-to-day experience, which is different from a career. Parents are participants in the services delivered to their children and often see gaps that may not be apparent at a policy level.

Deb: I think the parent's most important role is to convey the urgency and reality of the need to change the systems and philosophies in serving children with disabilities and their families. It's also to model and advocate for parent-professional collaboration in a way that demonstrates its value, and to make sure that the process and changes stay focused on actions that will truly be helpful to families and children being identified, served and empowered.

The parent's most important role is to convey the urgency and reality of the need to change...

Deb Russell holding her son, Daniel, with daughter, Margaret watching from her crib

Kathy: To me the most important role is to bring reality to the proceedings. Parents can also bring up turf issues when others are uncomfortable doing so, to help the group focus.

Rachel: My main task as an ICC parent is to advise, based on my family's experience.

Parents can bring up turf issues when others are uncomfortable doing so...

Bob: As a parent I try to focus on each of the issues as it will pertain to the family and the child. If nothing else, I try to have the issue restated in a different format, which may attract others into furthering the dialogue on the issue. I am not naive enough to believe that the issues are not talked about outside the meeting or that only the key department members are doing the talking. But when the meeting begins I can become that wild card or stray bullet that can waylay the best of strategies and change the outcome.

Linda: The most important role of a parent on the ICC is to represent a position that (presumably) no other member can, that of a consumer. Secondly, often parents can bring up issues which others may feel pressure not to. Parents' allegiance is to "the cause," rather than concerns related to the agencies, elected officials, etc.

Bob Boyce and son, Steven

Sue: When I think about my duties on the ICC, I envision a pyramid structure, and the task at the top of the pyramid (the one with the highest priority) is to be a constant reminder of why the ICC has come together and to interject a family-oriented perspective into all of the ICC's work. On the surface this may seem rather simple, but far too often the realities of family, in all of its shapes and forms, are left by the wayside amidst egos, turf battles and mounds of paperwork. Everything else I learn and all other responsibilities I take on filter down the pyramid from this main objective. We have certain issues that no one else can even be aware of, and we need to keep our own agenda, too. We can't be expected to erase that.

You live these issues on a day-to-day basis if you're a parent, and that is a different experience.

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Jeanette: The most important role of parents on the ICC is to be impartial in their alliances with systems in order to bring each of them into the process. Systems may have some difficulty letting go of their own issues, concerns and priorities, but parents have a perspective that crosses agencies and can attempt to model the way to work with all of them. This is not an easy thing to do, but if parents are perceived as for or against a certain system, their ability to affect change will be hampered. In a sense, this requires parents to reach beyond their personal experiences, not to forget them, not to discount them, but to apply them to the big picture. I guess reality is the other issue. ICC parents who were interviewed by Susie Perrett and Lisbeth Vincent[2] said overwhelmingly that they brought reality to the Council. Maybe "reality" isn't the right term. Maybe what we need to say is that you live these issues on a day-to-day basis if you're a parent, and that is a different experience. It's not better, it's not worse, but it is different. That does change your perspective.

How do I find out what is expected of me? Everybody is going to expect something different, because everybody has their own idea about what parent participation is for. It may help to find out what is expected of the ICC as a whole. Is its focus policy development, policy approval, policy implementation? It is also important to remember that parents may come to Council with issues that are important for them to address.

Jeanette: I think that a number of parents get appointed to a Council and drop out of their own agenda. People really do come to these meetings with their own agendas. It is okay for a parent to have an agenda, too, and not just to be trying to meet others' expectations. You need both pieces. You need to know what you're there for and what your interests are, what you're really committed to working toward, but you also need to see where that fits in the priorities of the Council, in order not to be wasting your time or be totally frustrated.

How do I figure out what's going on at first? It's probably never too early to start asking questions, because it's revealing to find out how many other people on the committee don't know the answer, either. There is no such thing as a stupid question. What is important is to direct the question to the best source.

Kathy and Ana Richardson

A parent mentor (experienced parent ICC member) is often a good source of information and direction to other possible sources. Find a parent mentor — a parent who is a past or experienced member of the ICC. They can tell you who the other members represent and what their particular interests are. A mentor can help you understand and interpret what you hear and see at ICC activities.

Rachel: Everyone was wonderful in helping me get started. They clued me in about where to go, when, and who all the people were. Parents as well as professionals have been very kind. The written information provided before each meeting has also helped me to be an effective ICC member.

Sue: My experience has been that welcoming is a two-way street. When I was able to extend myself to other Council members, as with greetings and conversation, most of them reciprocated. Over a course of time, more and more information and contacts have been shared. I thought I was received rather cautiously at first, almost as if I were delicate or I might cry. We need to keep in mind that professionals on this level might not have had experience working side-by-side with parents. Parents can build new foundations by remaining true to the agenda of children and families while they are familiarizing themselves with the priorities of the Council

Kathy: It helped that I already had relationships with some of the key players beforehand. I think this allowed me not to be terribly intimidated. Prior knowledge of the issues also helped. I feel that I've been well received myself; however, parent issues in general aren't a priority, at least at this time.

Bob: I recall that other members expressed general interest in me and in how I came to the ICC. I was listened to and in turn I listened. I sat next to a mental health professional, also a man, who was very understanding. He allowed me to interrupt with questions, and he talked me through the issues and some of the underlying politics. If the members simply acted on the issues that are being discussed, then the meetings would be easy to follow. But knowledge of the underlying relationships and intrigue that interlace the discussion and performance of the committee is needed to be able to effectively interact with the agency personnel.

How can I find a mentor? A mentor is a trusted guide. Trust develops over time and is often based on compatibility of concerns and values. It is important to find out who previous ICC parent members are. Through committee work and other early intervention activities, you can meet parents who are interested in early intervention and the ICC. You can stay in touch with other interested parents by phone or at meetings.

Kathy: One of the things that was most helpful to me in getting started was having an experienced parent mentor. My mentor is not a former parent representative of the ICC, so I don't mean this in a formal sense. I was lucky enough to meet a parent who has a great deal of experience in many areas, and I've learned much from her. She was a former staff person at the Indiana lead agency for Part H and in fact recommended me for my appointment.

Deb: I was already personally experienced and knew many other families across the state who had shared their experiences about the different programs and variations in services across the departments, public and private sectors, and the state. The biggest blessing was that my best friend who has a child with disabilities was appointed a parent representative to the Council with me. We were close personally and as advocacy partners, so we could process the meetings, support each other at the meetings, and deal with the frustrations together. When she moved out of state, it was a huge loss. (Conversely, the period when I was the only parent representative attending the Council was my lowest). I knew some of the players in the departments from working with them on other activities, so I could concentrate on just getting to know the new faces, not everyone. I was an experienced board and advisory board member and staff. I think it is hard to learn how to be an advisory council member while serving on such a revolutionary kind of council.

Cindy: I didn't have any parent mentors before me. My opportunity for parent mentors came from connections with parents from other states. When I met the parent who was chair of the state ICC — wow! That really inspired me to recognize qualities in myself to become a leader.

Linda: It was helpful for me to meet with a Council member thought to be "neutral." In my case, the personnel preparation person who had been a member for one year prior to my joining. This was done because I initiated it after feeling lost after two meetings. A formal parent mentoring system would be great!

How do I get reimbursed and what can I get reimbursed for?

States are authorized to reimburse ICC parents for their time and expenses related to ICC participation. It's important to identify a single point of contact to answer questions and get reimbursement forms. This person should be identified immediately upon appointment. Some local councils also pay parents expenses to attend meetings.[3]

Cindy: I get travel expenses and child care. They reimbursed me the cost to pay a nurse to watch my daughter so that I could attend meetings. Sometimes it has been difficult to have the up-front money for gas to travel to the meeting.

Linda: I have no problems with reimbursement, other than timelines — it usually takes 60 days. My job allows me to attend, therefore I don't request the stipend, only travel and expenses. Many people don't realize how much additional time and effort is involved, in reading materials, preparing for the meeting, networking, making up work from the time I took off work, arranging sitters, asking my husband to change his work schedule to accommodate my attending Council meetings, etc. I view this as all part of being a volunteer, the "thousand points of light" idea, so I don't really want to be reimbursed for this — just acknowledgment for the effort, particularly since I work full-time and have two kids with special needs.

Rachel: When meetings include an overnight, the state pays for the hotel directly. I am reimbursed for transportation and meals. I use Family Support to pay for child care. Sometimes someone offers me a ride and that helps, especially if they can pick me up at my house rather than my having to take a bus to that person's office.

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Kathy: I'm paid for attendance at each meeting and reimbursed for parking and mileage. Reimbursement is not usually timely, however.

Bob: I get reimbursed for mileage and I get a *per diem* rate for meals. If it is necessary to stay overnight, a room is provided for me. If I need day care for my son, I can be reimbursed. If I lost a day's wages I could be reimbursed for lost wages up to $50.00. The largest incentive is being able to interact with the department personnel and having some effect on the system. The information gathering is the best incentive that I know of. That is why I make it a point to be involved in the ICC.

Deb: Travel, meals and lodging are reimbursed. Nursing care is paid for my son through a contract with our nursing agency, so it does not count as income. This was done for parents whose families receive SSI, Medicaid, etc.

Sue: In Illinois, ICC parent representatives get reimbursed for all expenses incurred doing ICC work, including child care. In the spring of 1991, the Council voted to also provide a parent stipend which would reimburse parents for their time if they are unemployed or will lose wages. There was some opposition to this, because "parents have always volunteered their time," among other reasons, but after discussion, the majority of the Council saw the benefits and voted in favor of reimbursing parents for their time as well as expenses.

ALICE: I've never seen a law that's family centered!!! This IS a curious thing!!! What, that crazy Rabbit! What is she doing??

WHITE RABBIT/PART H COORDINATOR: Can't you see? It's very simple! I'm planning to implement a comprehensive, coordinated, interdisciplinary, community-based program of early intervention across this whole state!!! QUICKLY!!!

ALICE: I'm going after that P.L. 99-457, even though I'll probably never get reimbursed!!!

Notes, Questions & Comments:

...but Alice had got so much into the way of expecting nothing but out-of-the-way things to happen, that is seemed quite dull and stupid for life to go on in the common way.

Chapter 2

"The Pool of Tears"

In which Alice learns about the ICC and the lead agency

What is the relationship between the ICC and the lead agency?

A single state agency is chosen as lead agency to administer the infants and toddlers program in each state, so that one agency is responsible for handling the federal money and for assuring that services are available. The ICC is to "advise and assist" the lead agency, but the lead agency has ultimate authority to administer the state's program. What the relationship looks like varies from state to state. The political environment in each state is constantly changing, which influences the relationship. It is important to know how much influence the ICC has in planning and implementing services.

Currently states have the following lead agencies: [4]	
Education	**21**
Health	**18**
Human Services	**8**
Mental Health	**4**
Other	**7**

Jeanette: This is the real $64,000 question!!! It is not a measurable entity! The ICC has had a very difficult time defining it's role in relation to the lead agency. It is an important question for each Council as a whole to answer, and can be most delicate where the issues of politics and personality enter in. However, it is critical for parents to be involved at the policymaking level. It really becomes an issue of proving yourself in terms of understanding issues, being assertive when the need arises, and timing your energy to last for the duration.

Kathy: In Indiana the lead agency is (or seems to be) constantly going through structural or administrative changes. I don't see how the ICC could have major impact on this agency amid the confusion; however, I could be wrong. I haven't been a member long enough to tell.

Bob: Our ICC institutes, guides and refines policy. We are not given the power of policy making under our state legislation, but we do have an interagency agreement that all policies will come before the ICC for comment and referral. In Pennsylvania, we have two lead agencies: Departments of Public Welfare and Education. Each agency is very territorial. Each wants as much power and money, as they can control. They want to see how big they can make their turf, thus their power within the government. Neither agency likes the other and looks for ways to outmaneuver the other. The ICC is placed in the middle. I think we act as a buffer and maybe a check and balance for the agencies. The other members on the committee that are parents or private providers act to diffuse and fragment the posturing of the lead agencies. I believe that this tempering of agendas is helping foster cooperation that has been unknown in Pennsylvania government before the inception of the ICC. I think the agencies now have a forum where they are allowed to be and can be more honest and truthful.

Linda: I believe that the ICC has minimal-to-average influence on the lead agency. It all has to do with controlling the agenda, controlling information, networking and strategizing, which is their job. I have to do all of the above but in my spare time.

Rachel: I think the ICC has a lot of influence on the lead agency. Our ICC Chair is an administrator in the lead agency, which may have something to do with this.

Jeanette and Katie Behr

Who is on the ICC? The IDEA Amendments of 1991, which update P.L. 99-457, establish who is on each state's ICC. Representatives of certain agencies are automatically members. At least three members must be parents of young children eligible for early intervention. These requirements may change as Part H is reauthorized by the U.S. Congress in late 1991.

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Cindy: There are two of us [parent representatives] who have remained on the Council since the beginning. Agencies send different representatives if the designee can't attend. As parents, if we miss a meeting, we can only hope that families' views are not forgotten. Also the people that are employed by agencies change their jobs. I will always be a parent.

Jeanette: The issues really are longevity for one, and perseverance. Sometimes I think that the parent's role is to hang in there as long as they can and in a sense reeducate the professionals that come along. You build a relationship with professionals in certain positions and from certain agencies, but they may change in the course of your term, and you then have to begin again. Sometimes you don't begin in the same place, you can start in a different place, but you need to again build that relationship. I really think the people that hang in the longest are the ones that have a degree of success.

What roles do subcommittees play? Much of the Council's work may be delegated to subcommittees focused on topics such as service coordination, funding issues or transition to preschool. Subcommittees' work may then be reported back to Council for approval or other action. Subcommittee work can be a good way to get to know more about early intervention, the ICC and individuals who play key roles in your state.

Sue: I think a subcommittee is a good place to really roll up your sleeves and work on the nitty gritty issues of an early intervention service delivery system. Illinois' ICC has subcommittees for specific issues which we have identified as critical for our planning. These subcommittees include: personnel standards, program standards, finance, legislation and public awareness. Recently, we approved the formation of a new standing committee which has been named the Family Support Committee. The major force behind the creation of this committee is the concern that family-centered principles be interjected in all areas of council business as well as the ability of this specific committee to support ICC parents, cultivate parent leadership and expand ICC access to parent input. The Family Support Committee will have a 4:1 ratio of parents to professionals. I am very excited about this committee because of the potential vehicle for input and support it represents and because I am, by the way, the chairperson!

Jeanette: One thing that's been helpful is figuring out how subcommittees work into the bigger picture for Council. I think sometimes Council meetings are very generic, and they're about bigger issues, and they're not always getting nuts and bolts kinds of things accomplished. But a subcommittee, like Sue was talking about, on family support, or a subcommittee dealing with IFSP or a subcommittee on case management, which is what Minnesota has, is where parents are also expected to serve. It can be a substantial commitment, but it also can be more rewarding, because it's more focused. You have a chance, anyway, of understanding the issues and really accomplishing something. It's worth considering as a parent what subcommittees you would be willing to serve on. What kind of commitment could you give and really accomplish something in that arena?

The issues really are longevity and perseverance.

Cindy: One of the most helpful opportunities came at a subcommittee meeting for the Individualized Family Service Plan. The Part H Coordinator suggested connecting with a professional who worked with parents. I found the information offered by this person wonderful. This has been what has kept me going.

Rachel: I learned about early intervention through a series of workshops conducted by the Parent Education Project. Also, someone at my son's early intervention program suggested that I be asked to serve on the state's Screening and Assessment Committee, part of the Part H planning process. I learned a lot about 99-457 by going to those meetings.

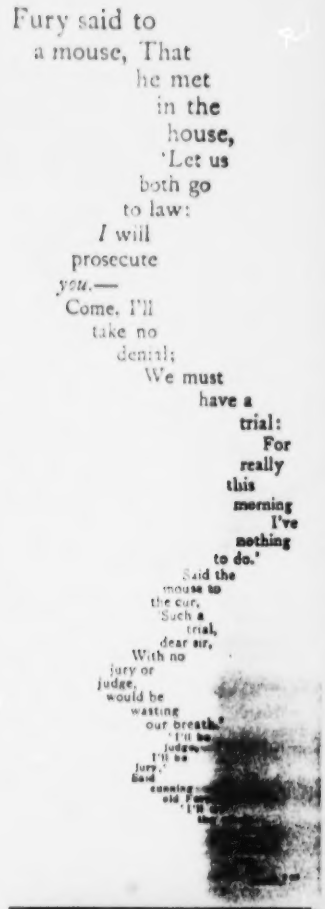
ALICE: Let's see, here's a door called Definition of Developmental Delay. Now, that one's locked up tight!!! Here's one marked Procedural Safeguards. Boy, is that a heavy one! I wonder if anyone knows what a comprehensive multidisciplinary evaluation is??? These doors are all locked!!! Hmmm, IFSP! Perhaps this will unlock one of these doors! There's rust on these locks...these doors must have been shut long ago. And the locks are huge. The key is so small and simple! Another little door. It says COLLABORATION on it and the key fits beautifully!!! I'll just peek in through here. My goodness! I can see the loveliest GARDEN OF FAMILY CENTERED SUPPORT!!! How I long to get out of this long dark tunnel of locked systems and wander about among those beds of bright professionals and those cool fountains of resources!!! But anyone who wants to get in there must certainly change their size, their turf, their status quo!!! But I would change if I only knew how!

Notes, Questions & Comments:

ALICE: Dear, dear! It's so hot in here! How queer everything is! And yesterday everything went on as usual, all of us in our separate systems without all this interagency stuff. I wonder how I fit in here? Have I changed? How do I know what move to make here if I don't know the rules and the rules seem to keep changing? I am so very tired of being all alone here!

Notes, Questions & Comments:

"Speak English!" said the Eaglet.
"I don't know the meaning of half those long words,
and, what's more, I don't believe you do either!"



What should I say about myself and my family? Personal stories can powerfully illustrate a point under discussion or support a value or an outcome. The ICC is an effective forum for change on behalf of many families and children, but not effective for resolving personal child and family issues or past grievances. The clearer you are about your own values and priorities, the more concise and effective your stories are likely to be. Stories, both positive and negative, should be relevant to the topic being discussed. Keep in mind that the way you present your child may have a long term effect on the way people come to view your child (and other children). People first language ("My daughter has Down Syndrome," rather than "I have a Down's baby") helps people view children as individuals rather than as diagnoses.

Consider the impact of a parent's story that focuses on the accomplishments of a child and/or family as they grow and develop. Stories that include the strengths are as important as difficulties.

Rachel: I told them my name, that I was a parent, and about Jonathan, my son. I told them about my experiences in trying to get testing and help for Jonathan. Nobody suggested that I tell my story, but I thought it would help them see that I know the system pretty well.

Linda: I had no opportunity, other than informally, to talk about my background or family, except when I make a reference when a particular issue is discussed.

Bob: I said my name and those of my family members. I explained that I was a parent and gave the disability of my child. I told what I did for a living and how understanding my wife was to allow me to lose wages and time with the family to attend these meetings. I stated how important I believed the ICC was and how I hoped that I would be of service and contribute effectively to the outcome of the ICC. Throughout the coming year, I told stories which further defined why I held certain beliefs and criticisms of policy, departmental organization or interpretation.

Kathy: Some members of the Council seem to be more interested in my affiliations than my family (or maybe more comfortable talking about those than family.) I have not been asked to share "my story" for the Council, however, I have discussed my family with many Council members during casual conversations.

"A Caucus-Race and a Long Tale"

In which Alice tells her story

3

Chapter

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Cindy and Jessica Norwood

Cindy: I remember sharing a story about a meeting to decide whether or not to continue life support on behalf of my daughter, where I felt valuable time was wasted assuming she would die. So I thought we couldn't waste time with negative assumptions, we needed to move forward with high expectations. We were struggling with whether or not to include children "at risk". There were people who felt we would never be able to serve all children anyway, so why should our definition be that broad?

When should I tell my story? One of the reasons you are involved is to share your story to help shape decisions. Sharing your story gives an experiential basis for your participation. Your experiences as a parent and family member are part of your credentials for being involved. Sometimes parents embarrass themselves by telling personal and painful details of their story before they have a chance to learn the ground rules or get to know the people. It helps if people get to know some positive qualities about you before you reveal your vulnerabilities. A parent's story may be more effective if used indirectly or with individual Council members in social interactions.

Jeanette: As a parent on an ICC, I have not shared a great deal about my child, family or background. It is more like snippets, or pieces of information, that specifically pertain to the issues at hand. For example, the ICC developed a definition of "at risk" that was not supported by the written position statements of systems. Although this was a difficult situation for the Council, and I personally was disappointed in the response, I said (as Chair) that based on my experience of living with a child who has autism, who is very clear about her disagreements, it was at least preferable to deal with differences openly, rather than avoiding the issue.

The most difficult thing to do is to judge when and where the emotional impact of a parent story will "work". It is a judgment call, but my rule of thumb is that it has to be worth the cost, in a sense. If I choose to share a personal experience, it must be a good experience for me, as well as the listeners.

How can I broaden my base of information and experience?

Although parents bring a unique personal experience to their Council position, parents also represent more broadly parents of children who are eligible for early intervention in their state. It is important to make connections with other families, so that their concerns and issues can be brought to Council.

Deb: I did not start to get involved in activities on behalf of children with disabilities until my kids were over two. I got on Council when my family was no longer dependent on the services, so I could speak my mind without being too fearful that I was threatening my own family's services. Since my children were five when I joined the Council, I had some perspective, but I knew lots of parents who were just beginning the process, so I was often reminded of the painful realities, needs and wishes of that time.

Sue: I enjoy meeting and talking with parents every chance I get! When I am out and about with my daughter, other parents do approach me and I usually do not hesitate to offer my phone number. Those relationships keep me grounded in reality and refuel my fire when I wonder if I can possibly make a difference. Also, the ICC parents in the Great Lakes Regional Group have been inspirational! I think that having a connection with parents in parallel positions can inspire a comradary that gives strength and confidence to all.

ALICE: Curiouser and curiouser! Now I'm growing very large! I can go to hearings and give testimony on what it's like to be a parent of a kid with disabilities!!!

Notes, Questions & Comments:

It sounded an excellent plan, no doubt, and very neatly and simply arranged; the only difficulty was, that she had not the smallest idea how to set about it...

Chapter 4

"The Rabbit Sends in a Little Bill"

In which Alice discovers the interesting history and nature of early intervention

Where did early intervention come from? How did it get started? Some states have for many years provided services for infants, toddlers and preschoolers through hospitals, private providers and public agencies. In 1986 P.L. 99-457 established the right to a free, appropriate public education for children with disabilities from the age of three. It also established a new federally supported program for children under three and their families, referred to as Part H. The Part H program is for children from birth through age two who have developmental delays or who have a diagnosed condition which has a high probability of resulting in a delay. States may serve children who are at risk of delays because of environmental and/or biological factors. Each state must adopt a definition of developmental delay and establish which categories of children are eligible for services.[5]

Kathy: Other parents, including my mentor, taught me about P.L. 99-457 initially. Involvement on the local ICC was helpful in learning about it, also.

Linda: I learned about 99-457 through Council materials, readings shared by my "neutral" Council member and other professionals I personally knew. Information about early intervention services in Illinois has been obtained only through contacts I have made through my job with a local education agency.

Linda Colson Pearlstein with daughters Sarah and Lisa.

Steven, Bob and Fern Boyce

Bob: I learned about 99-457 from an advocate during my due process hearing. I learned about early intervention when my son was diagnosed as being deaf. We were phoned and offered services. Learning about services in our state came much later when I accessed an advocacy organization and became involved in their planning sessions for lobbying for more funds for Early Intervention. I cannot ever remember anyone sitting my wife and I down and explaining the law and how Pennsylvania was implementing it and how it would affect my son and my family.

Jeanette: When I go back and read the federal regulations, that's when I get fired up. If you counted the number of times that "parent" occurs in that, it might be kind of interesting. I once counted the number of times that they say "assessment", and it's 41 times. It made me think: Oooh! We better pay attention to this. When you read all the rules and regs, it's such a strong role that parents have at every level. As I read it, I wish that parents could get that. It's not as lengthy as trying to sit down and read the whole law.

The law itself was an inspiration.

Deb: The law itself — its vision — was an inspiration. Everything else on Council was in turmoil. We did not even get most of the way through the agendas of the first years of meetings. I learned about the new law and developing councils from the national parent network newsletter of the Association of the Care for Children's Health. It told exactly how to find out about the plan for our state, and about parent members on the Council, and gave examples about what other parents were doing to impact the implementation around the country. I learned about early intervention as it was before 99-457 through having my child "fall through the cracks" until he was nearly two years old.

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What should early intervention look like? Everywhere early intervention should be family-centered, collaborative, oriented to positive outcomes for children and families, and culturally sensitive. Early intervention looks different in every state and in every area, because it should respond to the needs in the community. Your state's application for funding under Part H, which is submitted to the Office of Special Education Programs (OSEP), should describe what early intervention services are available in the state. A copy of the application should be available from the lead agency. In some states communities are required to prepare local plans. The intent of this law is to respond to the unique concerns, priorities and resources of each eligible child and family. They need to be responsive to a variety of lifestyles, cultural backgrounds, income levels, etc.

Sue: I can't emphasize enough the value of connecting with other parents in order to expand yourself as an individual and to help promote family-centered principles. All council members may not understand how specific issues impact on the realities of family life. There are so many variables to keep in mind! In Illinois the Family Support Committee is being designed to increase council responsiveness to the uniqueness of "family." Also, one of our ICC goals for a service delivery system is to have flexibility as a cornerstone so the communities can respond to service delivery in a way that fits their citizens and resources..

I can't emphasize enough the value of connecting with other parents...

Rachel: Along with other black members (there are three of us), I'm able to add a black perspective. For example, in talking about consent, we talked about our community's tradition of taking care of other people's kids. If a parent isn't able to be there for their kids, someone else jumps in — neighbor, aunt, grandmother, whatever. The kids relate to that person as their parent. The system isn't always respectful of that tradition among black people.

From a recent Head Start Policy Memorandum:

- Stereotypes and misinformation about cultures of different groups interfere with growth, communication, and respect.
- Stereotypes are learned: they are perceived and nourished by ignorance, lack of information and interaction. Culture can influence values, perceptions and behaviors. Minority groups also may share stereotypes that can affect perception of themselves and of other groups.
- Institutional and personal biases are values or practices which favor one group or culture, by race, sex, income, physical attributes or age. Institutional biases are reflected in practices and behaviors of the dominant group which devalue minority groups and cultures...Since culture is rooted in people's emotional commitments and guides their moral and aesthetic systems, it surfaces as attitudes and actions of "the right way" and "the wrong way." It is above all about valued relationships, about what is a worthy person and about how things are made valuable. *It gives life meaning.* [Emphasis added.]

PHYSICIAN EAGLET: The race is over! We've got P.L. 99-457! But who has won?

DODO E.I. TEACHER: Everyone has won and all must have prizes! How can we tell if we've collaborated without a prize?

Notes, Questions & Comments:

The Caterpillar and Alice looked at each other for some time in silence: at last the Caterpillar took the hookah out of its mouth, and addressed her in a languid, sleepy voice...Alice felt a little irritated at the Caterpillar's making such very short remarks, and she drew herself up and said, very gravely, "I think you ought to tell me who you are, first."

5

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"Advice from a Caterpillar"

In which Alice meets a Caterpillar who gives her curious advice about how to get respect, information, and support

What do I need to be an effective ICC parent member? Parents who have served on ICCs have identified three critical elements: Respect, information, and support.

Jennifer and Sue Walter

Deb: Our agendas always have an item where the Council gets reports from both the state agency representatives and the parent representatives. This makes me feel valued.

Sue: I was the first parent on our ICC and the only one for several months so I hope that I am forging a position of respect and honor for parents who come after me. As I look back, I wish I could have shortened the amount of time it took me to feel comfortable to speak up even though I believe that I am now in a position to present issues and be listened to. I am often offered information and/or contacts by council members or staff as well as a "good job" fairly often. I hope that future parents might have a smoother transition—I will do everything in my power to assist. Patience and courage are essential and work well with respect, information and support.

Patience and courage are essential...

Jeanette: The most helpful thing for me in becoming more effective on the ICC is to form partnerships with other Council members. There is another parent who sees things I don't always catch. There are also advocates, both on the Council and in the audience, as well as professionals who are committed to family-centered outcomes, in both word and deed. Working with these people, seeking information, using them as a sounding board, and listening to their perspectives has increased my effectiveness.

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Kathy: I feel that I've had a number of advantages as a Council member who was appointed in Council's third year: prior knowledge of P.L. 99-457; attending workshops and conferences; listening to parents; having an experienced parent mentor; and being on a local ICC.

Bob: I am still not sure that I am effective. The jargon and acronyms that the professionals use is forever cluttering my comprehension. The Department of Public Welfare has their data base of information with which they are knowledgeable. Then the Department of Education enters with their jargon. Each knows how the others will affect their agency because they work with this set of parameters every day and network with each other. I, on the other hand, know little of the interactions among departments or the jargon or the Federal Regulations with which all must comply. **IT IS A BATTLE TO UNDERSTAND ENOUGH TO PARTICIPATE.** My ego has been deflated so many times with my ignorance of these things that sometimes I just must leave the meeting to regroup my psyche and reaffirm my worth to myself.

Where can I get information? You can get information directly from parent advocacy groups such as Associations for Retarded Citizens, The Association for Persons with Severe Handicaps, United Cerebral Palsy. These national associations, and others, have state and local affiliates and publish newsletters and other information sources. National organizations like NEC*TAS and Mental Health Law Project publish volumes of information on P.L. 99-457. NICHCY (National Information Center for Children and Youth with Disabilities), which can be reached by calling 800-999-5599[7], is a good source of information and contact with many, many other groups. Each state must establish a central directory to provide information about early intervention services in the state. Parent training and information centers (PTIs) offer information geared to parents. There are now 60 funded PTIs. As of this summer there will be one in every state. There is a national network of PTIs that links them and disseminates information through them which is called the Technical Assistance Program for Parents (TAPP).

NEC*TAS (National Early Childhood Technical Assistance System) has facilitated several supports for parents:

1) At the last two Partnerships for Progress national meetings (Sponsored by the Federal ICC), ICC parents have come a day early or come in for a separate meeting.

2) There have been several conference calls over the last year for State ICC parents.

3) In the Coalition Quarterly, a national newsletter for parents of children with disabilities, there have been two-page additions on early childhood for ICC parents.

4) On SpecialNet there is an electronic bulletin board called PIP (Programs Involving Parents). Every month PACER Center in Minnesota now posts information for ICC parents, including information about the federal ICC. PACER also mails that information on a monthly basis, since many people do not have access to SpecialNet.

5) In the recently completed handbook for ICC chairs, a section on parent involvement is provided.

6) A national meeting of ICC Parent Representatives was sponsored in September of 1991.

How can I find people who will offer support? Contacts with parents who have participated in similar activities, either in your state or other states, are a valuable resource. For example, these materials were developed by parents and others in the seven-state GLARRC area interested in supporting ICC parents. As someone who has been involved in early intervention you have probably had a chance to meet other families of children who have used early intervention services. Parents who have been ICC members are good contacts. Other opportunities for meeting parents exist through parent support groups, advocacy organizations, parent training and information centers, training and educational sessions for parents.

Jeanette: I really would like to see the suggestion that the parent on the ICC bring another parent along, even if they're not on the ICC. If they don't know another parent that's on the ICC, they can bring another parent to be in the audience and observe. It's like going to an IEP meeting. If there's two of you, you feel a lot more supported than if you're alone. I know that could be real difficult for someone coming from a distance, but if they knew someone in the area and could go with them, it's somebody to debrief with as well. I need to talk to people after a meeting and say: Well, what did you think? What went well? What didn't go well?

Bring another parent...If there's two of you, you feel a lot more supported than if you're alone.

Sue: The GLARRC parent connections have been particularly helpful as are continued contacts with other parents and parent organizations. However, one of the loneliest, most exasperating times for an ICC parent representative is the long drive home after an intense Council meeting. We don't have the opportunities to debrief with colleagues over coffee or lunch. My office is my kitchen! This is the downside of being that unique individual who can bring up delicate issues and whose allegiance can not be claimed by bureaucracy. It has been helpful for me to seek out people who regularly attend our Council meetings and seem to have a more neutral stance. I like to talk with people who I can get honest feedback from even if it means constructive criticism. I value honesty.

How can I identify my strengths as a Council member? Each person brings unique gifts and contributions to the ICC. Some people have a no-nonsense attention to the task at hand. Others attend to the needs of individual members and give lots of support. Some are careful thinkers and analyze problems for the group. Some ask lots of questions. Some pay attention to detail, others see the whole picture in its broader features. Everyone brings knowledge and experience in one area or another. The variety of members' backgrounds helps make a group more effective.

Jeanette: It seems to me that finding some way for parents to do some kind of personality assessment could be extremely helpful, because knowing what your personality style is sometimes sheds a lot of light on how people operate in a group. If you have a particular personality on your Council that you tend not to gravitate towards, really that can be a person

that can balance out your attributes. You can get into a personality conflict when you don't know that not everybody that comes from that agency is that way. That's their personality. It can get you beyond some of those issues where you think that this person is very standoffish or whatever it is that bugs you. It's their style, that's all it is. I think it gets you beyond judging people too quickly and getting into that mistake. In Minnesota we asked the advocacy organizations to give us that training and let parents take that tool. The PTIs were very willing to do that. Those types of tools are offered in other arenas, like community education, too. Parents might look for personality assessment tools offered in other settings.

...It is too easy to focus on what we don't know and feel intimidated or frustrated instead of focusing on the value of our unique knowledge about families.

Sue: The personality assessment* we used at the regional ICC parent conference in September helped me realize the value of having a variety of personality styles participate around the Council table. I have a new respect for the individuality of each Council member, including myself. I think that this is especially valuable for parents because it is too easy to focus on what we don't know and feel intimidated or frustrated instead of focusing on the value of our unique knowledge about families.

CATERPILLAR: Who are you?

ALICE: I hardly know anymore. I was just a parent this morning but I think I've changed to an advocate...

CATERPILLAR: Explain yourself! What do you mean by that?

ALICE: I'm afraid I can't. To be so many different sizes and have so many different roles...It's all so confusing!... I wish the creatures wouldn't be so easily offended!

CATERPILLAR: One side will make you grow taller and the other side will make you grow shorter.

ALICE: One side of what? The other side of what?

CATERPILLAR: Of the P.L. 99-457 mushroom! You can pick the role you want to play if you know the law!

Notes, Questions & Comments:

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"It wasn't very civil of you to sit down without being invited," said the March Hare. "I didn't know it was your table," said Alice, "it's laid for a great many more than three."

Alice felt dreadfully puzzled. The Hatter's remark seemed to her to have no sort of meaning in it, and yet it was certainly English. "I don't quite understand you," she said as politely as she could.

6 apter

"A Mad Tea Party"

In which Alice attends her first ICC meeting

How should I prepare for an ICC meeting? Bring materials you received ahead of time, such as an agenda for the meeting. Take something for taking notes. Know where the meeting will be held and where parking is available. Allow enough time to get to the meeting location. Know whether you are expected to buy your own lunch or whether lunch is provided. If it has not been provided in meeting materials, request the phone number where you can be reached, so that you can notify your family or care providers.

Sue: Each member of the Council initially received a binder with a copy of the law, our Executive Order, names and addresses of Council members, among other important memos and documents. There is room to store and add on as you wish. I call it my Council bible and I use it! Being prepared can give you an advantage and can help you feel more confident.

Jeanette: Reading the volumes of information handed out at meetings (at least skimming through it and filing it for further reference) has been the key to figuring out what is going on. It is very difficult to be effective on an ICC without some extensive background information. Reading the testimony that was given before this law was enacted has added to my understanding as well as provided some inspiration to keep working on the issues. I have also asked a lot of questions in informal settings, about jargon, about programs, about how a particular system works, and asked a number of different people, both professionals and advocates, in order to get a more complete picture. It is really helpful to know someone who can give you information.

How does the ICC operate as a group? What are meetings like? Just as each individual brings unique contributions to the group, each group has a unique identity. Groups generally vary in how welcoming they are to new members. They also differ in whether they are more group-centered or more leader-centered. Some groups are more formal and structured than others. Most groups follow something like *Robert's Rules of Order, Revised*, which can be found in most libraries. ICCs are run either by an Executive Order from the Governor or by state legislation. Local ICCs may adopt Bylaws to guide how business is transacted. The group may change with time or as membership changes.

These unstated rules guide the way the group operates as much as any Bylaws or legislative mandates, but may be harder to find out about. This is another area where a parent mentor can help point out the unwritten rules. There are also political "ins and outs." It helps to observe body language, participation, and be clear on your background information. If you don't understand something, ask for information from a person you do trust. Meeting length may vary from a half-day to two days, with an overnight. The professionals who attend usually come in business clothes. The issues that are considered are often complex, leading to lengthy discussion. Many issues are not resolved at a single meeting, so it is important to attend regularly.

Linda: I believe meetings are successful or less successful depending on who is chairing the meeting and how skilled, sensitive, involved, political, etc., the Chair is. The best meetings are when there is give and take, everyone can feel comfortable stating their position. The worst meetings are when you feel "railroaded", agenda items are pushed through, there's no real discussion, pertinent information is withheld or only comes out after intense questioning. There are also times when questions and comments are ignored. I also believe that a lot of people like to hear themselves talk and don't really add anything substantive, as in remarks that people want to be on the record in support of something. So, everything and nothing can happen at a meeting.

Everything and nothing can happen at a meeting.

Kathy: Though the Council is chaired by an agency representative, it is quite clear that the Part H Coordinator runs the meetings.

Jeanette: Something that is very helpful for me is to have a sense of humor about the work involved on the ICC. The issues are complex, sometimes the atmosphere of the meetings is so emotionally charged, it has been helpful to have some fun. As Chair I brought baseball hats to the Council members, using the analogy of working as a team, and clearly stating that was a priority for my term as Chair.

Cindy: I recall a discussion between two professionals that seemed to go back and forth, back and forth. No one else commented on anything and their language flew right over my head. I raised my hand and said, "I really can't follow this. I have to break the words down to find out the meaning and I can't keep up. Could you use smaller words?" Everyone laughed. It seemed to relieve the tension and others said afterward they were lost as well.

How do I find out who is at the meeting? As a new member it is not out of line to ask that members introduce themselves at the beginning of the meeting and wear name badges.

Kathy: At my first meeting I had to ask the group to introduce themselves. I was pretty uncomfortable at first. About halfway through the meeting I had a comment about something and briefly introduced myself first.

At this point everyone seemed to realize that they hadn't done introductions, the discussion stopped, introductions were made and the discussion resumed. I should point out that the group seemed apologetic, and I don't feel that this was intentional at all. Since that meeting, introductions are always done before we begin.

Sue: Periodically we receive an updated list of Council members (and designees) with addresses and phone numbers for our records but I feel free to ask for an update if I feel the need. I think it is reasonable to be supplied with this type of information. We also use name plates at our Council meetings in addition to introductions. Parents should make these needs known to the coordinator and/or staff.

How do I find out who I can trust and what I can say to whom?

Each member has interests that influence what they say and do. People have interests that come from paychecks as well as from personal history and relationships. Building relationships with professionals is an important role for parents of ICCs. Use this as an opportunity to learn more about the system each professional represents. But don't hesitate to honestly and respectfully share your perspectives at the consumer level. If you are uncomfortable sharing your perspective at first, ask questions about the system or service a person works for. It is also an opportunity to get to know people as people who also struggle with daily schedules, family commitments, etc.

Sue: My personal rule is to try to observe, ask questions and listen very carefully while simultaneously avoiding being judgmental. This can be hard at times because of all the variables involved (turf issues, individual personalities and relationships, etc.) in addition to the intermingling of moral principles about caring for people and the financial ability to do so. And to top that off we must remember we are all only human. I have to honestly say that in spite of the good relationships I have with most of my fellow Council members, there is no one that I trust unquestioningly. I can't help feeling that even though I may have a great deal of respect and admiration for someone, I must reserve the right to stand back, ask my own questions and try to remain true to my own values.

MAD EDUCATION HATTER and HUMAN SERVICES HARE: No room! No room! Parents can't be involved in policy! They can't make decisions! This is an ICC tea party and who invited you?

ALICE: There's plenty of room! You need some reality here!! You need me!

ALICE: That was the strangest tea party I ever was at in all my life!!

Notes, Questions & Comments:

"I quite agree with you," said the Duchess, "and the moral of that is — "Be what you would seem to be" — or if you'd like it put more simply — "Never imagine yourself not to be otherwise than what it might appear to others that what you were or might have been was not otherwise than what you had been would have appeared to them to be otherwise."

Chapter 7

"The Queen's Croquet-Ground"

In which Alice plays legislative croquet with the Queen of Taxpayers and actually makes public policy

What new roles could I take on, as I gain experience? There are a variety of roles related to public policy that parent ICC members may assume. Chairing a committee or the Council itself may be a way to have a stronger voice. Working for legislation that supports family-centered early intervention is another.

Jeanette: I testified on the reauthorization of 99-457. It was very interesting. I thought it was a lot of fun. I survived it, and I didn't start crying, which was my goal. I had a good time, and I think I got some points across. The funny thing is that there were lots of things that were exactly as people had said that they would be, but they didn't use the red light, green light and yellow light business, so we could have gone much longer than we did. The next time what I really want to do is prepare something on each of the 14 components from the family's perspective. I didn't do that, thinking I wouldn't have enough time, but I really would have had enough time. I put recommendations from the Great Lakes ICC parents' in the record, in my written testimony, so they're part of the Federal Register.

Sue: I was a participant on the Illinois Special Joint Committee on Early Childhood Intervention. We met over a three month period to look at the issues surrounding early intervention and to review existing documents and research. At the end of a pre-designated time period, we submitted a report of our findings to the legislature which ultimately was woven into legislation. Participants on this committee included four legislators and six members of the public — I was the only parent. I seriously questioned my ability in the beginning, "Self, what have you gotten into this time?" But it was a very empowering, confidence-building experience. Now I am the chairperson of the new Family Support Committee and I am asking "Self" the same question. The bottom line is to not let those twinges of self-doubt stop you.

How do I know what the real issues are? Regular attendance helps you see over time which issues are brought for discussion again and again. Histories between people or agencies that we may know nothing about lead to undercurrents that affect people's positions on the real issues. The real issues are about how decisions that are made address the needs of individual children and families throughout your state. Once you have identified an issue you think deserves Council's attention, you can go to the Chair of the ICC and ask to be put on the agenda. Other members can also support your request for meeting time. There should

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be an agenda item for new business, during which new issues can be raised. Time-consuming issues raised during new business often end up tabled (postponed) for another meeting. If you want to assure that the issue is discussed at the next meeting, it is better to get time on the agenda in advance. Discuss your ideas with other parents and professionals to see if you can establish support before the meeting. If it is an issue that will be complex or time-consuming, consider the mechanism of the ICC. Would a subcommittee address your issue more completely? Are you willing to chair a subcommittee to work on it over time?

Kathy: I figured out fairly quickly that if I had something important to bring up, I needed to get on the agenda, and I had to figure out how to do this. This proved to be difficult during the recent legislative session, when last-minute information came up.

Jeanette: The Council meeting is not the appropriate time to bring up individual issues. Your personal agenda doesn't mean child-specific. You might gain some information on the way, but that's not what people are there for. We don't want people to think they're appointed to Council for their own child. It's really at a policy level that you want to effect some change. It's a critical part of parent involvement, in my way of thinking.

How do I identify other ICC members who will listen to my concerns?

It takes time to identify other members who share the same values and vision for early intervention. It is important to seek allies among those who pursue similar outcomes and share your concerns.

Sue: Once again, I think that observing and listening are very important. With proper information and mentoring, some of the stumbling blocks might be removed but developing relationships of respect and some amount of trust takes time, patience and effort. I think it would be misleading to suggest otherwise.

What is my constituency?

A constituency is the people you represent and speak for. Parents' constituency as a ICC member is parents whose children are eligible for early intervention. You speak best for people you know and whose concerns are familiar to you.

Deb: I represent all parents of children with handicaps in our state. I have special knowledge and experience of those with health needs and those who are not adequately served through the existing systems.

I represent all parents of children with handicaps.

Kathy: I wish there were an effective way to let families know that I'm representing them in this way. Though I have parent contacts in many parts of the state, I feel I could improve this with more support from the ICC.

Jonathan, Julius, and Rachel Grant

Rachel: I represent young kids and their families. I represent urban parents and minority parents, **but I also represent ALL parents.** I do feel, though, that Milwaukee often needs someone pulling for it especially.

Bob: Sometimes when I daydream or I cannot sleep at night, I ask myself that question, about how many people I am representing. First, I represent my son and my family. When I am dealing with something that in no way could impact on him, then I represent all with his disability, deafness. I do this because I know about deafness and what it has done to my family and what the system has done to my family because of his deafness. I must also generalize to all disabilities and try to do what I feel is best, knowing full well that I don't know about the disability in question.

Cindy: I got involved in a parent empowerment project and became a parent consultant with the project. This gave me a chance to hear other parents' perspectives and to begin to represent a constituency.

Sue: I try to use my personal experiences as the baseline for my task of representing children and families, but I think ICC parents should try to the best of their ability to stretch themselves beyond that baseline. By seeking connections with other individual families, I think that I have been able to expand and build on my ability to represent families and promote family-centered principles. Quite honestly, I have worried about the fact that all families may not have their realities properly represented. I know that as human beings it is not possible to truly imagine what it is like to walk in someone else's shoes. But I think the conscious effort to do so is what makes the difference when I am trying to illustrate various realities that I may not have experienced myself. My own desperate moments are vivid in my memory and push me to do as much as one person is able to give all families a voice.

ALICE: Would you tell me please, what you are doing?

LEGISLATIVE GUARD: Well, the fact is, we should have put more money into kids and families; we made a mistake with these budgets, so we're trying to shuffle around the programs to £ll a little bit of each program...but if the Queen of Taxpayers finds out we should all have our heads cut off, you know.

ALICE: I don't think they play fairly at all! These committees are stacked. The Speaker of the House is killing bills left and right. One can't hear oneself give testimony. And they don't seem to have any rules in particular. They schedule a committee hearing for 2 o'clock in the afternoon and end up meeting at 10:00 in the evening! And even then when you testify they might be writing notes to each other or balancing their checkbooks!

Notes, Questions & Comments:

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"Silence!" [said the King] and read out from his book.
"Rule Forty-two. All persons more than a mile high to leave the court." Everybody looked at Alice.
"I'm not a mile high," said Alice.
"You are," said the King.
"Nearly two miles high," added the Queen.
"Well, I shan't go, at any rate," said Alice; "besides, that's not a regular rule; you invented it just now."
"It's the oldest rule in the book," said the King.
"Then it ought to be Number One," said Alice.

apter

"Alice's Evidence"

In which Alice prepares to leave ICC Land and considers what it was all about

How do I become a mentor? A parent who has served on an ICC long enough to understand some of the complexities of the position is an invaluable resource to parents who may just be joining. Parents who are completing terms may have time and energy to invest in a new member. Offering information, support and respect can be a first step. Attending meetings with a new member allows for preparation beforehand and debriefing afterward.

Jeanette: Sharing information and also seeking information can be a way to start a mentorship that runs both ways. I'd like to see encouragement for the idea of being a mentor and being mentored. I think that on different issues parents play both roles. You can mentor somebody on one issue and then turn around and get some help from them on another issue. There's so much information out there. One of the advantages of being on the Council for me is that you really do get a lot of information. I try to remember people a particular piece of information might be useful to, because of the specific disability they deal with or because of the areas they're interested in. I try to send things off to people. When I'm really stuck on an issue, I turn around and call them for something else. I guess that to me is the key to mentoring. It's sharing information, integrating it with the other information you already have and then seeking new information when you need it.

Jennifer Walter at computer

How do I know if I've made a difference? Sometimes it is difficult to see a direct result from your efforts. It really takes time for people to understand issues from another's perspective, and it also takes time for parents to learn the system's issues. Planning to pace yourself for long-term involvement and setting goals is also helpful. Also, it is not always apparent to the individual what the effect of systems advocacy is. However, being clear on your own priorities may help you see progress.

Linda: The bottom line is parents do make a difference. Parents and professionals must collaborate to bring about the best services. The problem is, not all the professionals have figured that out yet.

Jeanette: I don't think anyone should expect immediate results. You really have to be committed to hanging in there and working on issues over time.

Cindy: I've really been inspired by the work done by Project Copernicus[10] — the statement that talks about family-centered care being a journey instead of a final destination. We can't just write things up and think we have it, not if what we're doing is supposed to reflect families' concerns. Like other parents, my hopes and dreams for my daughter Jessica continue to grow and change, as she does. So what we're doing is a continual pursuit of being responsive to the hopes and dreams of families, which are always changing.

Sue: Sometimes it is helpful to stop right where you are and take some time to reflect on what has happened over a course of time, from past to present. Change is difficult to assess when you are in the middle of it and it is only upon reviewing where you were and where you are now that you see how far you have come. Then, you can take a deep breath and look forward again.

The bottom line is parents do make a difference.

ALICE: What a curious and wonderful dream! Children with disabilities will achieve things no one thought possible! If we hang on to the dream and work with families, children with disabilities will grow up to have dreams of their own![11]

Daniel Russell and friend

Notes, Questions & Comments:

[1] A copy of *Alice in ICC-Land* may be found in Appendix A.

[2] As part of an activity for the Family Concerns Committee of the Division for Early Childhood of the Council for Exceptional Children. A copy of the organization's resolution concerning family participation is in Appendix B. An executive summary of the committee's survey of ICC parents is in Appendix C.

[3] See relevant OSEP memo in Appendix D.

[4] A complete listing of Part H Lead Agencies can be found in Appendix E.

[5] Federal regulations require that states have all policies in place for the beginning of Year 4 of the Part H program and that services be available for all eligible children at the beginning of Year 5. The U.S. Congress recently allowed states two additional years for planning purposes prior to full implementation of services.

[6] U.S. Department of Health and Human Services (1991) Memorandum on Multicultural Programming.

[7] A directory of national organizations and their telephone numbers is located in Appendix F.

[8] *The Personal Style Survey*, (1987), Performax Systems, Inc.

[9] These recommendations may be found in Appendix G.

[10] *Project Copernicus* of The Kennedy Institute, 2911 East Biddle Street, Baltimore, Maryland 21213 (301) 550-9700.

[11] From "A Window of Opportunity", a speech given by Robert Silverstein on November 3, 1988 before the national meeting of Project Zero to Three.

Footnotes

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endix

"Alice in ICCLand"

ALICE IN ICC-LAND

A Play in One Act
by
Jeanette Behr
Assisted by Shirley Kramer

This play was written in the summer of 1990 with assistance from Shirley Kramer of the Minnesota Interagency Coordinating Council and Dennis Sykes of the Great Lakes Area Regional Resource Center (GLARRC). The idea for the play developed during two regional meetings of ICC parents sponsored by GLARRC in February and May of 1990. It was given its premiere performance on September 17, 1990 at a regional ICC parent conference in Bloomington, Minnesota entitled "The Art of Storytelling." The author is a parent representative to, and chairperson of, the Minnesota Interagency Coordinating Council. The final scene was written by Jeanette and Shirley in preparation for the performance of the play at the International Division for Early Childhood Conference in St. Louis, Missouri on November 15, 1991. We hope that the views expressed will be accepted in the same good humor with which they were produced.

Please feel free to reproduce and utilize this script as you may see fit..

Cast of Characters

(Listed with the Players in the Original 9/17/90 Production)

Narrator: ..... **Shirley Kramer**
Alice/Parent: ..... **Cindy Norwood**
White Rabbit/Part H Coordinator: ..... **Sue Walter**
Public Health Nurse Mouse: ..... **Deb Johnson**
Case Manager Duck: ..... **Liz Irwin**
Therapist Parrot: ..... **Deborah C. Holtry**
Dodo E.I. Teacher: ..... **Jeanette Behr**
Physician Eaglet: ..... **Richard Burden**
PTI Caterpillar: ..... **Dennis Sykes**
Cheshire Advocat: ..... **Deb Russell**
Mad Education Hatter: ..... **Gwen Jensen**
Human Services Hare: ..... **Patty McMahon**
Public Health Door Mouse: ..... **Deb Johnson**
Queen Taxpayer: ..... **Roberta Sample**
King Governor: ..... **Bob Boyce**
Common Sense Executioner: ..... **Deb Tisdale**
Legislative Guard #1: ..... **Brad Johnson**
Legislative Guard #2: ..... **Sue Endress**
Alice's Sister (Narrator): ..... **Shirley Kramer**

(The scene opens on Alice looking through many pieces of paper. The scenery and props may be minimal or elaborate. Many props may be mimed.)

• **ALICE:** Let's see here, IEP, ISP, IHP, medical report, insurance forms, list of equipment needs, all this paperwork!! It's such a hot day and all this technical jargon makes me feel very sleepy and stupid. I wonder if the true joy of functional outcomes is worth all the meetings and efforts?

(She lays her head down briefly; just then the WHITE RABBIT runs by)

(Carrying a picture of a mushroom with P.L. 99-457 written on the back. Shows both sides as she runs across stage)

• **WHITE RABBIT** *(exclaiming loudly)*: "Oh dear! Oh dear! I shall be too late with the year four "Part H" application! When **IS** that deadline??? Oh dear!"

(Alice jumps to her feet, watches as Rabbit crosses stage, jumps up on a chair)

• **ALICE:** I've never seen a law that's family centered!!! This **IS** a curious thing!!! Why that crazy Rabbit! What is she doing??

• **WHITE RABBIT** *(turns and shouts to Alice)*: Can't you see? It's very simple! I'm planning to implement a comprehensive, coordinated, interdisciplinary, community-based program of early intervention across this whole state!!! QUICKLY!!! (Rabbit jumps off chair as if down a rabbit hole.)

• **ALICE** *(with conviction)*: I'm going after that P.L. 99-457 even though I'll probably never get reimbursed!!!

(Alice runs after the rabbit, jumps onto chair and 'down' the rabbit hole. She lands with a thump, sees White Rabbit hurrying by with stacks and stacks of papers)

• **WHITE RABBIT**: Oh my fourteen components, how late it's getting!

• **ALICE** *(looking up at the lights)*: Look at those lamps hanging up there. Says federal rules and regulations but they are rather dim!

• **ALICE** *(looks from side to side at imaginary doors, as in a long hallway, squints and reads as she peers at each 'door')*: Let's see, here's a door called Definition of Developmental Delay...*(tries imaginary door)* now that's locked up tight!!! Here's one marked procedural safeguards (tries 'door' again) boy, is that a heavy one! I wonder if anyone knows what a comprehensive multidisciplinary evaluation is??? These doors are all locked!!!

(Alice sees small golden key on small table)

• **ALICE** *(reads letter printed on key)*: Hmmm IFSP! Perhaps this will unlock one of these doors! There's rust on these locks...these doors must have been shut long ago. And the locks are huge...the key is so small and simple!

Look! Another little door *(Alice stoops down)*...it says COLLABORATION on it and the key fits beautifully!!! I'll just peek in through here... My goodness! I can see the loveliest GARDEN OF FAMILY CENTERED SUPPORT!!! How I long to get out of this long dark tunnel of locked systems, and wander about among those beds of bright professionals and those cool fountains of resources!!! But anyone who wants to get in there must certainly change their size, their turf, their status quo!!! But I would change if I only knew how!

(Alice finds bottle labeled DRINK ME)

• **ALICE:** Well I'll try it! *(drinks from bottle)*: What a curious feeling! I must be shrinking! Now I've changed enough to get into that lovely garden!

(Narrator changes large key for small key. Puts cake underneath table)

(Alice runs back to table but can't pick up key)

❦ **ALICE** *(wails):* No matter what size I am I can't seem to do this alone!! *(She sits down and cries. Spots cake under table.)*

❦ **ALICE** *(sniffling):* What's this? It says EAT ME. If it makes me grow larger, I can reach the key; if it makes me grow smaller, I can creep under the door: so either way I'll get into the Garden of Family Centered Support, and I am willing to change to any size to do that!

(Eats cake)

❦ **ALICE** *(shouting):* Curiouser and curiouser! Now I'm growing very large! I can go to hearings, and give testimony on what it's like to be a parent of a kid with disabilities!!! Or go to work for a PTI center! Good-bye feet!

(Alice runs to table and gets key. She looks down a tiny door)

❦ **ALICE:** But now I'm way too big to get in there!!!

(Alice sits down and begins to cry again, shedding gallons of tears. Narrator puts up circle of blue waves to signify pool of tears around Alice)

❦ **ALICE:** No matter what I do I can't seem to figure this out alone!

❦ **WHITE RABBIT** *(with a pair of white kid gloves in one hand and a large fan in the other, muttering loudly):* Oh! Won't OSERS be angry if I've kept them waiting!

(Alice feels so desperate that she is ready to ask help of anyone)

❦ **ALICE** *(in a low timid voice):* If you please, Ma'am.

(The Rabbit starts violently, drops the white kid gloves and the fan, and scurries away into the darkness, saying...)

❦ **WHITE RABBIT:** A parent!!! How did she get in here???

(Alice walks up to fan and gloves, she keeps fanning herself all the time she's talking)

❦ **ALICE** *(thinking aloud):* Dear, dear! It's so hot in here! How queer everything is! And yesterday everything went on as usual, all of us in our separate systems without all this interagency stuff. I wonder how I fit in here? Have I changed?? How do I know what move to make here if I don't know the rules and the rules seem to keep changing?? I am so very tired of being all alone here!

(Suddenly Alice realizes the fan has made her tiny again. She drops it on the floor)

❦ **ALICE:** Now I can get into the garden!

(Alice crosses stage and 'falls' into pool of tears, where she is joined by the Public Health Nurse Mouse, a Case Manager Duck, a Therapist Parrot, a Physician Eaglet and an E.I. Teacher Dodo Bird. All pretend to swim around and around in the 'pool of tears')

❦ **PUBLIC HEALTH NURSE MOUSE:** Well, I think what's needed here is a fair assessment of the family!

❦ **CASE MANAGER DUCK:** According to the county plan we are about to drown!

❦ **THERAPIST PARROT:** Just move those legs, everyone! Range of motion and sensory integration will pull us through!

❦ **PHYSICIAN EAGLET:** Take some tylenol and call me tomorrow!

❦ **DODO E. I. TEACHER:** Let's sing! *(starts in on)* The wheels on the bus go round and round...

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• **ALICE** *(going over to edge of pool):* My goodness it's crowded in here! Let's get out and get dry!

• **DODO E. I. TEACHER:** We must have a caucus race to get dry. Then we'll figure out how to do all this collaboration! Everyone in a circle! Now start running!

(All on stage start running in circles)

• **PUBLIC HEALTH MOUSE:** Where are we going? How can we do this?

• **CASE MANAGER DUCK:** Case Manager! Service Coordinator! Facilitator! You're doing it all wrong!

• **DODO E. I. TEACHER:** Eligibility criteria! Lead agency! You're wrong!

(Ad lib comments from systems)

• **PHYSICIAN EAGLET:** The race is over! We've got P.L. 99-457! But who has won?

• **DODO E. I. TEACHER:** Everyone has won and all must have prizes! How can we tell if we've collaborated without a prize?

(All on stage except Alice go off looking for prize)

(Alice walks across stage to mushroom and PTI Caterpillar, smoking a pipe. They look at each other for a bit in silence)

• **PTI CATERPILLAR:** Who are you?

• **ALICE** *(shyly):* I hardly know anymore. I was just a parent this morning but I think I've changed to an advocate....

• **PTI CATERPILLAR:** Explain yourself! What do you mean by that?

• **ALICE:** I'm afraid I can't. To be so many different sizes and have so many different roles...it's all so confusing!

• **PTI CATERPILLAR:** It isn't.

• **ALICE:** Well it feels very strange to me?

• **PTI CATERPILLAR:** You! Who are you!

• **ALICE:** I think you should tell me who you are first!

• **PTI CATERPILLAR:** Why?

• **ALICE** *(feeling angry and about to walk away):* Who will give me all the information I need to change the systems??

• **PTI CATERPILLAR:** Keep your temper! What size do you want to be?

• **ALICE:** Well I'd like to be a little bigger and not have to keep changing all the time, you know.

• **PTI CATERPILLAR:** No, I don't know!

• **ALICE** *(to audience):* I wish the creatures wouldn't be so easily offended!

• **PTI CATERPILLAR:** One side will make you grow taller and the other side will make you grow shorter. *(Turns and walks off stage)*

• **ALICE** *(Thinking aloud to audience but not directed to the Caterpillar):* One side of what? The other side of what?

❦ **PTI CATERPILLAR** *(shouts from off stage):* Of the P. L. 99-457 mushroom! You can pick the role you want to play if you know the law!

(Alice mutters thoughtfully to herself, wanders across stage, is startled by Cheshire Advocat who has quietly come on stage, grinning)

❦ **ALICE:** Could you tell me, please, which way I ought to go to get this law implemented?

❦ **CHESHIRE ADVOCAT** *(grinning):* That depends a good deal on where you want to get to.

❦ **ALICE:** I don't much care where...

❦ **CHESHIRE ADVOCAT:** Then it doesn't matter which way you go!

❦ **ALICE:** —so long as it's family centered and people work together! What sort of people live about here?

❦ **CHESHIRE ADVOCAT:** Well there's the Human Services Hare and the Mad Education Hatter in that direction. Visit either you like. They're both mad.

❦ **ALICE:** But I don't want to go among mad people.

❦ **CHESHIRE ADVOCAT:** Oh you can't help that! We're all mad here. To try and change these giant, complicated systems is mad. You're mad too! Do you play croquet with the Queen of Taxpayers today?

❦ **ALICE:** I should like to but I haven't been invited yet.

❦ **CHESHIRE ADVOCAT:** You'll see me there!

(Alice walks across stage to table where Mad Education Hatter, Human Services Hare and Public Health Door Mouse are sitting with lots of papers, cups, etc. The Public Health Door Mouse is asleep, while the other two are using her as a cushion, resting their elbows on it and talking over its head)

MAD EDUCATION HATTER and HUMAN SERVICES HARE take turns with these lines. Each shouts "no room" alternately, each reads one of the next lines; together they say "This is an ICC tea party and who invited you?" They then individually each say "No room!! No room!!"

❦ **MAD EDUCATION HATTER and HUMAN SERVICES HARE** *(cry out when they see Alice coming):* No room! Parents can't be involved in policy! They can't make decisions! This is an ICC tea party and who invited you? No room!! No room!!

❦ **ALICE** *(indignantly):* There's plenty of room! You need some reality here!!

❦ **HUMAN SERVICES HARE:** Well, here. What do you think of this definition? (gives Alice a blank sheet of paper)

❦ **ALICE:** There's nothing written here!

❦ **MAD EDUCATION HATTER:** Well, how can we write something unless we know how much it's going to cost us??

❦ **HUMAN SERVICES HARE:** Cost? Who said 'cost'? There's no money for this! There's no time for this! How long is a year 9 months? 12 months? 16 months?

❦ **MAD EDUCATION HATTER:** Time! What month is it? Is this Year Three or Year Four?? What is our dispute resolution system?

❦ **HUMAN SERVICES HARE:** What dispute? Who's arguing? You're <u>wrong, wrong, wrong</u>!!!

• **MAD EDUCATION HATTER:** Wake up that Public Health Door Mouse! She's sleeping again. *(pretends to pour tea on Mouse's nose)*

• **PUBLIC HEALTH DOOR MOUSE** *(shaking itself awake)*: A decision? Have you made a decision? Have you decided something at last? What about working with families? Are you willing to try it now?

• **MAD EDUCATION HATTER** *(looking very puzzled)*: Families?

• **HUMAN SERVICES HARE** *(stage whisper)*: So what is this IFSP? Is this an entitlement to services or what?

• **PUBLIC HEALTH DOOR MOUSE:** We need some data. We have no data!!

• **ALICE:** But what about telling families what's available in simple and concise terms?

MAD EDUCATION HATTER, PUBLIC HEALTH NURSE, HUMAN SERVICES HARE (all stop and stare at Alice)

• **ALICE:** Well, I really don't think...

• **MAD EDUCATION HATTER** *(interrupts Alice loudly)*: Then you shouldn't talk!!

• **ALICE:** It can't be so complicated if we know what we're working toward! *(Gets up and walks off in great disgust)* That was the strangest tea party I ever was at in all my life!! *(walks across stage)* The Garden! I've finally gotten in!! I wonder who lives here?

(Alice walks over to two legislative guards. Guards are wearing hats - one is Republican, one Democrat. The Democrat is putting money on a "money tree", the Republican takes the money off the tree and pockets it.)

• **ALICE:** Would you tell me please, what you are doing?

• **LEGISLATIVE GUARD #1:** Well, the fact is we should have put more money into kids and families; we made a mistake with these budgets so we're trying to shuffle around the programs to fill a little bit of each program....but if the Queen Taxpayer finds out we should all have our heads cut off, you know.

• **LEGISLATIVE GUARD #2** *(shouts with fear)*: The Queen! The Queen!

(The two Legislative Guards throw themselves flat on the floor, face down. Alice stands nearby)

(The King Governor and Queen walk in slowly with any others to make up the procession. When they reach Alice, the Queen stops)

• **QUEEN TAXPAYER** *(severely)*: Who is this?

• **ALICE:** My name is Alice, I'm a parent...

• **QUEEN TAXPAYER** *(looking at Legislative Guards)*: And who are these?

• **ALICE** *(boldly)*: How should I know? I didn't vote for them!

• **QUEEN TAXPAYER** *(furiously)*: Off with her head!! Off with—

• **ALICE** *(shouts back)*: Nonsense!

• **KING GOVERNOR:** Consider, my dear: she is just a parent...

• **QUEEN TAXPAYER** *(to Legislative Guards)*: Get up! What <u>have</u> you been doing here?

• **LEGISLATIVE GUARD #2:** Well, we should be united in getting more funding for <u>all</u> kids and families but....

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QUEEN TAXPAYER: I see! No more taxes! Off with their heads!

ALICE *(to Legislative Guards):* You won't be beheaded! We'll pay far more in the future if we don't keep these programs funded. *(Alice stands in front of the guards. The guards sneak offstage. The King, Queen, et. al. move across stage)*

QUEEN TAXPAYER: Are their heads off?

KING GOVERNOR: Their heads are gone, if it please your Majesty!

QUEEN TAXPAYER: That's right! Can you play legislative croquet?

(Everyone looks at Alice)

ALICE: Yes!

(Everyone gets mallets (pieces of rope or shall we use pink plastic flamingos??) and koosh balls. The players all play at once without waiting for turns, quarrelling all the while, and fighting for koosh balls. Alice tries very hard to get her flamingo under her arm and hit a koosh ball but either the flamingo slips or someone else steals the koosh ball. No one is able to hit a koosh ball but everyone keeps up the effort and commotion)

CHESHIRE ADVOCAT *(only head appears behind cardboard. Alice notices right away):* How are you getting on?

ALICE *(complainingly):* I don't think they play fairly at all! These committees are stacked, the Speaker of the House is killing bills left and right. One can't hear oneself give testimony. And they don't seem to have any rules in particular. They schedule a committee hearing for 2 o'clock in the afternoon and end up meeting at 10:00 in the evening! And even then when you testify they might be writing notes to each other or balancing their checkbooks!

(The creatures all quarrel so!)

CHESHIRE ADVOCAT: And how do you like the Queen?

ALICE: Not at all! She's so extremely—*(Alice notices Queen listening to her)*—likely to win, that it's hardly worth introducing any bill that calls for adequate funding..

KING GOVERNOR *(to Alice):* Who are you talking to?

ALICE: It's a friend of mine—a Cheshire Advocat.

KING GOVERNOR: I don't like the looks of it at all. Looks like someone who tries not to bow to political pressure. But it can kiss my (clears throat) hand if it likes.

CHESHIRE ADVOCAT *(dryly):* I'd rather not!

KING GOVERNOR: Don't be impertinent! *(to Queen)* My dear! I wish you would have this advocat removed!

QUEEN TAXPAYER *(steps out of character for just an instant, says to audience):* I have one way to deal with any difficulty, large or small—(as Queen again)—Off with her head!! Cut her budget!!

KING GOVERNOR: I'll fetch the executioner myself! *(Walks to edge of stage)*

COMMON SENSE EXECUTIONER *(comes on with King Governor, arguing, over to Cheshire Advocat):* You can't cut off a head unless there's a body attached! This head is just the beginning! The body hasn't even shown up yet!

KING GOVERNOR: I don't like this grassroots organizing unless I'm in control of it! And she's trying to make it work!

♥ **QUEEN TAXPAYER:** Well, if something isn't done in less than no time, everyone will be executed!!!

♥ **OFFSTAGE VOICE:** The trial's beginning!!! The trial's beginning!!!

♥ **CHESHIRE ADVOCAT:** Come on! (takes Alice by the hand and starts to pull her to the side of the stage)

♥ **ALICE:** What trial is it?

(No one answers her, the Cheshire Advocat just continues to pull her to the side. The following characters hurry on stage: Public Health Nurse Mouse, Case Manager Duck, Therapist Parrot, Dodo Early Intervention Teacher, Physician Eaglet, PTI Caterpillar, Cheshire Advocat, Mad Education Hatter, Human Services Hare, Public Health Door Mouse, arrange themselves in a semicircle front left of stage. King and Queen take their positions on a raised section back right stage, so the 'trial' is set diagonal to the audience. As the characters come out there is much talking, whispering, and jockeying for the best positions going on. Ad lib. The Legislative Guards stand at attention, with notepads, one on each side of the stage. The White Rabbit stands beside the King.)

♥ **KING:** Guard, read the accusation!!!

♥ **LEGISLATIVE GUARD #1:** On the twenty-second day of May, one thousand nine hundred and ninety-one, the Committee of Labor and Human Resources, to which was referred the bill S. 1106 to reauthorize part H and for other purposes, having considered the same, reports thereon.

♥ **KING:** Consider your verdict!

♥ **WHITE RABBIT:** Not yet! Not yet! There's a great deal to come before that!

♥ **QUEEN TAXPAYER:** Call the first witness!

♥ **LEGISLATIVE GUARD #2** *(Honks bicycle horn, three times):* First witness!

♥ **MAD EDUCATION HATTER** *(Jumps up from chair still holding teacup which he/she shakes nervously):* It all started out as 'glue money'...and five years was definitely enough time to get something done...but there was this confusion about the lead agency and the funds were trickling down and trickling away and I'm a poor man your Majesty and most things trickled after that. Then the Human Services Hare said—

♥ **HUMAN SERVICES HARE** *(interrupts quickly and loudly, jumping to his feet):* I didn't!

♥ **MAD EDUCATION HATTER:** You did!

♥ **HUMAN SERVICES HARE:** I deny it! It's an issue of entitlement!!

♥ **KING** *(to all the 'creatures' and guards):* He denies it. Leave out that part about entitlement. If we ignore it long enough maybe it will just go away!

♥ **MAD EDUCATION HATTER:** Well, at any rate the Public Health Door Mouse said that the Hare was going to collaborate...

♥ **PUBLIC HEALTH DOOR MOUSE** *(who has been sleeping since sitting down is jabbed to wake up by creatures around her as soon as her name is read):* Hare?! Heir?! Heir apparent?? Here's a parent? A parent is here?!!

♥ **ALICE** *(jumping to her feet):* I'm a parent!!

♥ **QUEEN TAXPAYER:** Off with her head!!

♥ **KING** *(loudly, but as if to QUEEN only):* She's a blonde!! It won't make any difference!

❦ **PUBLIC HEALTH NURSE MOUSE:** Stop! Stop! She's at risk!! The point of this law is to promote capabilities and prevent—

❦ **DODO EARLY INTERVENTION TEACHER** *(jumps up, interrupts loudly):* P!! P is for prevention! P is for parent! P is for primary!!

❦ **PHYSICIAN EAGLET** *(jumps up and interrupts loudly):* P is for Primary Physician! P is for prescription! I must prescribe paternalistic care at a tertiary care center for modest capitation rates—

❦ **QUEEN TAXPAYER:** Capitate?? Decapitate!!!

❦ **DODO EARLY INTERVENTION TEACHER:** D! D is for denial! D is for—

❦ **CASE MANAGER DUCK** *(interrupting, jumps up):* D is for Duck!! *(says next line in sing-song voice as in Duck, duck grey duck)* Duck, duck, case manager duck! DUCK!!! Here comes case management!!!

❦ **OFFSTAGE VOICE** *(a loud wail):* Everybody duck!!!!

❦ **KING** *(with irritation):* Never mind!! Call the next witness!

❦ **LEGISLATIVE GUARD #2** *(honks bicycle horn three times)*

❦ **KING** *(aside to Queen):* Really, dear, you must try the next witness, it makes my head ache so. And who knows how many votes this bill is worth anyway?!

❦ **WHITE RABBIT:** The next witness is Alice!

❦ **KING:** What do you know about this business?

❦ **ALICE:** Nothing!

❦ **KING:** Nothing whatever?

❦ **ALICE** *(looking a little puzzled):* Nothing whatever except parents are a little like teabags! They don't know their own strength until they get into hot water.*

❦ **MAD EDUCATION HATTER AND HUMAN SERVICES HARE** *(in unison):* Hot water?! You're certainly in it now!!

❦ **CHESHIRE ADVOCAT:** Strengths? *(points to all the 'creatures')* You've all assessed her strengths and needs!

❦ **KING** *(emphatically):* That's unimportant!!

❦ **WHITE RABBIT** *(nervously):* You mean important!

❦ **KING** *(looking puzzled, mutters to himself):* Important...unimportant...important.

❦ **PTI CATERPILLAR:** Who? Whose needs are we meeting here??!

❦ **QUEEN TAXPAYER** *(rhyming):* What's the cost?

Who will be lost?

We're already in the red!

Off with her head!!

- **MAD EDUCATION HATTER:** Don't be rash!

  No checks, please.

  Just send cash!!

- **KING** *(decisively):* That's the most important piece of evidence we've heard yet!!! Consider your verdict!

- **QUEEN TAXPAYER:** Sentence first, verdict afterwards! Pay now, buy in later...first the funding, then the collaboration.

(As the Queen says these lines, all the 'creatures' join hands in a circle and dance around to the tune of Ring Around the Rosy)

- **ALL CREATURES:** Differential funding!

  Participation pending! *(Repeat verse??)*

  Cash it! Cash it!

  It all trickles down!

- **THERAPIST PARROT:** Stretch those arms out everybody! We don't write goals and objectives but we provide the movement!!

- **ALICE** *(loudly to the Queen):* Stuff and nonsense! The idea of having a sentence first!

- **QUEEN TAXPAYER** *(raging):* Off with her head!! Off with all their heads!! *(gestures at all the 'creatures')*

(Everyone looks frightened, slowly back offstage, except Alice)

- **ALICE:** Nonsense! We need to work together without all this fear and prejudgement! We need more keys! Accountability, interagency cooperation and coordination, not a whole new system!**

- **ALICE'S SISTER** *(shakes Alice's shoulder):* Wake up Alice, dear! What were you dreaming?

- **ALICE:** What a curious and wonderful dream! Children with disabilities will achieve things no one thought possible! ** If we hang on to the dream and work with families, children with disabilities will grow up to have dreams of their own!

---

* Betty Pendler, Exceptional Parent, Jan. - Feb. 1990.

** A Window of Opportunity P. L. 99-457 by Robert Silverstein, speech given November 3, 1988, before the national meeting of Project Zero to Three.

Notes, Questions & Comments:

FAMILY CONCERNS COMMITTEE

Division for Early Childhood of the International Council for Exceptional Children

Resolution to Encourage Family Participation in Service Development and Delivery

Adopted April 3, 1991

DEC supports the full participation of families in all levels of planning and implementation of services for young children with special needs and their families.

1. DEC believes that families need to be recognized as equals in the partnership of service development and delivery. To be truly collaborative, it is necessary for professionals to respect family values, priorities and knowledge. Professionals need to encourage and support families' participation in ways that capitalize on the expertise and resources which families bring to both the planning and implementation of services. It is also necessary for professionals to be sensitive and respect a family's right to choose the amount of their participation.

2. DEC recognizes that most family members will need orientation, at the beginning of their involvement in planning activities, in order to participate as equals. DEC encourages the development of orientation materials and activities which assist parents to "hit the ground running" when they join planning bodies and efforts.

3. DEC recognizes that in order to participate as equal planning team members, family members, it is necessary that family members be included in the system of information exchange on a continuous basis, not just at scheduled meetings.

4. DEC recognizes that in order to insure participation in planning bodies and activities by a diversity of families, full reimbursement for the costs of participation is necessary. This includes travel, per diem, and actual child care costs. When needed to assure participation, compensation for time or lost wages should be provided. DEC urges federal, regional, state and local agencies and planning bodies to fully reimburse these and any other costs associated with family participation.

DIVISION FOR EARLY CHILDHOOD SURVEY OF ICC PARENTS

Executive Summary

Parents Reactions to Serving as Representatives on State Interagency Coordinating Councils for Part H of PL 99-457

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"Executive Summary of DEC Survey of ICC Parents"

In carrying out both the letter and the spirit of P.L. 99-457, all State Interagency Coordinating Councils (ICCs) have included parents of young children with disabilities as representatives. The purpose of parent participation was to encourage parents to be involved from a policy level through an implementation level as State ICCs designed and implemented their early intervention systems. How has this worked out? A sample of parents from 25 states responded to an indepth telephone interview about their participation on State ICCs. The results include the following information:

- This was the first experience at the State level for 73% of the parents;
- 97% of the parents had children over three years of age;
- Parents spent an average of 21.4 hours per month on ICC activities;
- 75% of the parents did not receive any orientation when they first joined the ICC;
- Parents were active ICC members (67% participated in public hearings related to Part H; 57% helped develop products or reports from subcommittees or the full ICC);
- 80% of the parents received full reimbursement for expenses related to the meetings (mileage, per diem, etc.), while over 80% were not reimbursed for associated expenses, such as child care or lost wages;

- 70% of the parents viewed their purpose as "keeping the ICC real and honest" and 30% viewed their purpose as "knowing what family-centered really is." Only 44% believed that they were usually or always able to achieve these purposes;

- Parents rated their ability to contribute higher than average on a 5.0 scale; representatives of public education agencies were most often mentioned as not valuing parents' input;

- 48% felt that the ICC used their expertise effectively;

- 88% indicated more and better support and encouragement for parents is needed to increase their contribution to the ICC; suggestions for parental support included full reimbursement for expenses related to meetings, orientation procedures, and materials related to their participation.

The survey indicated that parents recognize that mandating their involvement in the State planning process for Part H does not guarantee them equal access to decision making or respect. Yet, they viewed their participation as worthwhile and seemed to understand that building a partnership is a process that takes time.

RECOMMENDATIONS:

1. Develop effective orientation procedures and materials in order to help parents "hit the ground running" as ICC members.

2. In order to ensure that the parents represent a more diverse group (ethnically and socioeconomically), reimburse parents for the full cost of their participation; and, explore mechanisms to cover parents' costs ahead of time rather than using a reimbursement system.

3. Develop policies at the federal, state, and local levels that govern terms of office and ages of children of parent representatives to insure that their participation is as equals in this partnership.

Lizbeth Vincent,

Susie Perrett,

Barbara Smith

& Gail Beam

Division for Early Childhood of the
International Council for Exceptional
Children 1991

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"OSEP Memo on Parent-Reimbursement"

UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF SPECIAL EDUCATION AND
REHABILITATIVE SERVICES

JAN 9 1990

Ms. Marlene Morgan
Executive Director
Arizona Department of Economic Security
P.O. Box 6123
Phoenix, Arizona 85005

Dear Ms. Morgan:

I have received your letter of November 21, 1989, in which you have asked for guidance and clarification about the reimbursement policies for Council members, specificially as it relates to parent members. As you are aware, parent representation on State Interagency Coordinating Councils (ICC) and active parental participation in ICC activities are at the heart of the Part H program philosophy. Section 303.602(b)(1) requires that Council members serve without compensation from Part H funds, but shall be reimbursed for "reasonable and necessary expenses for attending meetings and performing Council duties." Two exceptions to the "serve without compensation" are delineated in §303.602(b)(2) if:

(i) A Council member is not employed; or
(ii) A Council member must forfeit wages from other employment when participating in official Council functions.

You have posed the question about which Council members should be considered eligible for compensation. You specifically identified two types of parents on the Council: (1) a parent who is self-employed, and (2) a parent who is employed on a part-time basis. It is the intent of Part H to encourage parent participation in the decision-making functions of this program. In order to facilitate parent involvement to the fullest extent possible, certain considerations must be taken into account. In the case of the parent who is self-employed, participation in Council functions could potentially result in the forfeiture of wages from his/her business; therefore, that parent may be compensated for time spent on Council functions.

In the second instance, the parent, who is employed part-time may fall into either category for which compensation is permitted (§303.602(b)(2)) -- (1) the parent would have to forfeit wages from the part-time employment to participate in Council functions, or (2) the parent could be considered not employed during the non-employed portion of the week. In either case, funds under Part H may be used to provide compensation to the parent who is employed on a part-time basis.

400 MARYLAND AVE., S.W. WASHINGTON, D.C. 20202-2651

The regulations contain provisions to compensate parents who would not be otherwise compensated for participation in Council functions that clearly apply to the two parent employment situtations you have described. I hope this guidance will be helpful to the Arizona Interagency Coordinating Council, as well as your Attorney General's Office.

Please do not hesitate to contact me or Bobbi Stettner-Eaton with additional concerns or questions.

Sincerely,

Judy A. Schrag

Judy A. Schrag, Ed.D.
Director
Office of Special Education
Programs

NEC*TAS List of P.L. 99-457 Part H Lead Agencies
June 1991

	State	Lead Agency
1.	Alabama	Educational/Crippled Children's Servs(CCS)
2.	Alaska	Health & Social Services
3.	American Samoa	Health
4.	Arizona	Economic Security/Developmental Disabilities (DD)
5.	Arkansas	Human Services/DD
6.	California	Developmental Services
7.	Colorado	Education
8.	Commonwealth of Northern Mariana Islands	Education
9.	Connecticut	Education
10.	Delaware	Office of State Planning and Coordination
11.	District of Columbia	Human Services
12.	Florida	Education
13.	Georgia	Human Resources/Mental Health-Mental Retardation-Substance Abuse Services(MH-MR-SAS)
14.	Guam	Education
15.	Hawaii	Health/CCS
16.	Idaho	Health & Welfare/DD
17.	Illinois	Education
18.	Indiana	Mental Health
19.	Iowa	Education
20.	Kansas	Health and Environment
21.	Kentucky	Human Resources/MH-MR
22.	Louisiana	Education
23.	Maine	Interdepartmental Committee
24.	Maryland	Governor's Office of Children and Youth
25.	Massachusetts	Public Health
26.	Michigan	Education
27.	Minnesota	Education
28.	Mississippi	Health
29.	Missouri	Education
30.	Montana	Social and Rehabilitation Services/DD
31.	Nebraska	Education
32.	Nevada	Human Resources
33.	New Hampshire	Education
34.	New Jersey	Education
35.	New Mexico	Health & Environment/DD
36.	New York	Health
37.	North Carolina	Human Resources/MH-DD-SAS
38.	North Dakota	Human Services
39.	Ohio	Health
40.	Oklahoma	Education
41.	Oregon	Mental Health/DD
42.	Palau	Education
43.	Pennsylvania	Public Welfare
44.	Puerto Rico	Health
45.	Rhode Island	Interagency Coordinating Council
46.	Secretary of the Interior (BIA)	Education
47.	South Carolina	Health & Environmental Control
48.	South Dakota	Education
49.	Tennessee	Education
50.	Texas	Interagency Council
51.	Utah	Health
52.	Vermont	Education
53.	Virgin Islands	Health
54.	Virginia	MH-MR-SAS
55.	Washington	Social & Helth Services
56.	West Virginia	Health
57.	Wisconsin	Health & Social Services
58.	Wyoming	Health

RESOURCE ORGANIZATIONS FOR ICC PARENTS

(From the NEC*TAS Resource Notebook for ICC Chairs, 1991)

GENERAL

Association for the Care of Children's Health, 7910 Woodmont Ave., Suite 300, Bethesda, MD 20814. Phone: (301) 654-6549.

Beach Center on Families and Disability, Bureau of Child Research, 3111 Haworth Hall, University of Kansas, Lawrence, KS 66045. Phone: (913) 864-7600.

Carolina Institute for Child and Family Policy, CB#8040, 300 NCNB Plaza, University of North Carolina, Chapel Hill, NC 27599-8040. Phone: (919) 962-7374.

Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091. Phone: (703) 620-3660.

National Committee for Citizens in Education, 10840 Little Patuxent Parkway, Suite 301, Columbia, MD 21044.

National Early Childhood Technical Assistance System (NEC*TAS), CB#8040, 500 NCNB Plaza, University of North Carolina, Chapel Hill, NC 27599-8040. Phone: (919) 962-2001.

National Information Center for Children and Youth with Handicaps (NICHCY), P.O. Box 1492, Washington, DC 20013. Phone: (703) 893-6061 or (800) 999-5599.

National Information System and Clearinghouse, Center for Developmental Disabilities, Benson Bldg., University of South Carolina, Columbia, SC 29208.

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National Maternal and Child Health Clearinghouse/National Center for Education in Maternal and Child Health, 38th & R Streets, N.W., Washington, DC 20057. Phone: (202) 625-8400.

National Organization of Rare Disorders, P.O. Box 8923, New Fairfield, CT 06812. Phone: (202) 746-6518.

Technical Assistance Program for Parents, 312 Stuart Street, Boston, MA 02116. Phone: (617) 482-2915

GENETICS

Alliance of Genetic Support Groups, 38th & R Streets, N.W., Washington, DC 20057. Phone: (202) 625-7853.

MINORITY FAMILIES

Institute for Urban and Minority Education, Box 40, Teachers College, Columbia University, New York, NY 10027.

Intercultural Development Research Association, Suite 350, 5835 Callaghan Road, San Antonio, TX 78228.

PARENT SUPPORT

National Parent ... urce Center, CAPP Project, National Parent Network on Disabilities, 95 Berkeley ... Suite 104, Boston, MA 02116.

National Self Help Clearinghouse, City University of New York Graduate Center, 33 West 42nd St., New York, NY 10036.

Sibling Information Network, Connecticut's University Affiliated Program on Developmental Disabilities, University of Connecticut, 249 Glenbrook Road, Box U-64, Storrs, CT 06268. Phone: (203) 486-3783.

ICC PARENT REPRESENTATIVES OF THE GREAT LAKES STATES

(Illinois, Indiana, Michigan, Minnesota, Ohio, Pennsylvania, Wisconsin)

Recommendations Concerning ICC Parent Development and Support March 1991

Background

One of the many challenges presented by PL 99-457, Part H, is the development of new kinds of relationships between parents and professionals. New ways of relating are needed not only in planning and providing services to individual infants and toddlers, but also at the policy level, as parents and professionals serve together on Interagency Coordinating Councils (ICC) for Early Intervention.

Parents serving on state-level Interagency Coordinating Councils for early intervention in the Great Lakes states (IL, IN, MI, MN, OH, PA, WI) have participated in a regional networking activity since the fall of 1989. The activity has been facilitated by the Great Lakes Area Regional Resource Center in response to needs identified by parent representatives to its Advisory Committee. The activity has focused on addressing the needs of ICC parents for information, support, and training through their linkage with each other, existing parent training and information centers, and other resources. Two meetings were held which included the majority of ICC parents in the region, many representatives from parent training and information centers, and representatives from other interested groups. The second of these meetings was conducted in the format of a conference entitled "The Art of Storytelling", which was planned and organized by a smaller work group of parents selected from the larger group. This work group met two additional times, once to organize the conference and a second time to develop materials and resources which reflect the collective experience of the group.

Members of the group felt that they had learned much from this experience about ways to support parents in their role as ICC members, at both local and state levels. They were eager to share that knowledge with other ICC parents, with the professionals who serve on ICCs, and with others who want to support parents in this new role. The following recommendations were developed by the work group and have been reviewed in draft by all participants. They represent the best thinking of the group regarding the effective support of parent representatives to state and local ICCs.

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"Great Lakes ICC Parent Recommendations"

It is important that parents be valued and respected in their role as ICC representatives.

1. Parents value relationships with professionals who provide them with information and listen and appreciate their expertise. Actions such as the following empower parents:

- spending ICC meeting time on issues identified by parents;
- attending conferences concerning parent identified needs;
- explaining rules and procedures, both written and unwritten, official and unofficial;
- providing opportunities for reciprocity.

2. The relationship between parents and professionals on ICCs should be viewed as reciprocal; parents contribute and learn as do professionals.

3. The ICC needs to spend time developing an understanding of the parent representative's role and the benefits and value of parent participation.

4. ICC parents' time and expenses (e.g., travel & per diem, postage, copying, phone calls, child care, etc.) should be reimbursed. (See relevant OSEP Memo)

5. The age limit for children of ICC parents should be reexamined and made more flexible to increase continuity and to reap the benefits of the perspective of parents looking back at their child's early years.

6. The national early childhood TA provider (i.e., NECTAS) should have an ICC parent on its Advisory Committee if they are to include ICC parents as a constituency.

7. All these recommendations need to be implemented in a manner sensitive to the cultural and socioeconomic diversity of families.

ICC Parent Representatives need accurate and appropriate information in order to function effectively.

1. ICC parents identified these key needs:

- Shared experiences
- Listening friends
- Time for rest
- Timely and clear information

The above could be a starting point for exploring the needs of individual ICC parents and implemented in a manner sensitive to the cultural and socioeconomic diversity of families.

2. Orientation materials should be developed to meet a broad range of learning styles and preferences (e.g., written information, video, personal contact, mentoring, audio tapes, etc.)

3. Parents should be given clear information about their role, including being a spokesperson for other parents, at the time they are asked to join an ICC.

4. ICC Parents should be supported in connecting with a constituency of parents of young children and in receiving support and input from parents of older children. Parent Training

and Information Centers (PTI), advocacy groups, parent support groups, etc. may be helpful in establishing such connections. PTIs, in particular, need to examine their role in providing information and support to ICC parents.

5. Professionals and representatives of parent groups, advocacy agencies, PTIs, etc. should help ICC parents establish efficient ways to exchange information and gather input.

6. ICC parents should have access to a clearly identified staff-parent liaison to assist with reimbursement and other logistical issues.

7. ICC parents should have opportunities to be put on various mailing lists in order to receive pertinent information.

8. ICC parents should be supported in gaining free access to relevant electronic communication such as SpecialNet. An ICC Parent bulletin board should be established on SpecialNet. The current dissemination to ICC parents of information from the SpecialNet bulletin board "Programs Involving Parents" (PIP) by NECTAS is a good start in this direction.

ICC parent representatives experience support when they are connected to a variety of parents and professionals interested in the implementation of Part H.

1. In order to avoid isolation, ICC parents need meaningful relationships with a variety of professionals. Options and opportunities for the development of such relationships need to be provided.

2. State and local ICC parents in a given state should have regular contact.

3. ICC parents need opportunities to network with their peers in other states or locales (e.g., conferences, conference calls, planning committees, etc.).

4. Regional activities are an ideal size for facilitating networking among state ICC parents.

5. Parents leaving ICCs should be considered as possible mentors to new parents and compensated for time and expenses.

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"From the Heart"

To the Reader:

We have enjoyed the process of putting these thoughts to paper and hope that this document serves you well. We wish you great success in your efforts on behalf of young children and families. May you find the courage and persistence necessary for this important task.

Susan Walker Cindy Norwood Robert C Boyce

Dennis Lyles Leah Holden Jeanette E Bahr

Deborah D Russell Rachel Grant

Kathy Richardson Diane Gerst

— Your thoughts to which we bow...

It is your help we hope for now...

We are very interested in your thoughts concerning this book. Please copy (or tear out) and fill out this form. Thanks.

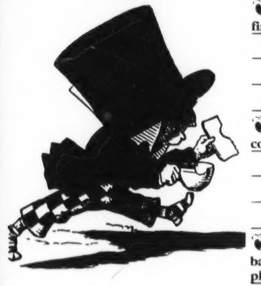
Was this book useful? If so, how did you use it?

What, for you, was the most useful information presented in this book?

What aspects of this book could be improved?

Your time — (sadly no fees)...

... "Just a moment, — If you please."



What types of follow-up information would you find useful?

If you used this book for a larger audience, who comprised that audience?

What do you think are the most important barriers to parent participation in state and local planning?

Sur

"...if you please"

Please share any success stories regarding parent participation which you would like to share.

Any other comments? (Please attach extra sheets if necessary)

Your Name:

Address:

Street

City State Zip Code

Phone: ( )

Please return to:

Dennis Sykes
The Early Integration Training Project
The Ohio State University
700 Ackerman Road, Suite 440
Columbus, Ohio 43202

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"Thank You"

We've discussed along the way

— So much to do and say...

"I'm glad we covered that!"

— You're a worthy advocat...

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